

**Children's Special Health Services (CSHS)
Family Advisory Council Meeting Minutes
May 20, 2006**

Welcome/Introductions/Announcements:

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Cheryl Klee, Twyla Bohl, Lisa Beckman, Donene Feist, Jennifer Restemayer, and Carla Peltier.

Present from CSHS: Kora Dockter, Sue Burns, Leann Bayman, Devaiah Muccatira, and Tammy Gallup-Millner.

Guests: Courtney Klee

Devaiah Muccatira, a new CSHS staff member, was introduced. He is the MCH Research Analyst/SSDI Coordinator. He relayed he was born in India but moved to the United States to finish his education. He has a wife and young child.

The following announcements were made:

- Tammy reminded members of the Family Connections Conference scheduled for June 14-16, 2006 in Bismarck, ND. CSHS staff members are involved with a Family Support panel and asthma presentation, both of which have been included as part of the training schedule. Family members relayed they had not had any problems getting family stipends to attend the conference.
- Tammy suggested that council members read the handout "Disaster Preparedness for Families of Children with Special Needs" prepared by the Florida Institute for Family Involvement.
- A reminder was given about the Youth Disability Leadership Conference, which will be held June 20-22, 2006 in Minot for youth ages 15-21. In future, CSHS hopes to actively promote the conference if information is available for outreach.
- A family representative is needed to attend the EMSC Conference June 19-22, 2006 in Washington D.C. If anyone is interested, they can notify CSHS.
- Donene suggested Florestine Grant be contacted as a potential member of the Family Advisory Council. She can be reached at (701) 854-2257. Donene met her at a family workshop day in Fort Yates.

Follow-up:

- February 2006 meeting minutes were accepted as written.
- The Review/Recommendation form was reviewed for the February 2006 meeting. Media activities related to asthma had been completed and included a press release and TV coverage. A newsletter article is still pending. Family support partners will be invited to the upcoming Clinic Coordinator meeting routinely scheduled in August or September. The initial draft of the Champions for Progress fact sheet for ND will be completed May 2006.

- Tammy routed a recognition letter that had been written for Dr. Sobus and relayed she had contributed to a plaque that had been given on behalf of many appreciative families and organizations. CSHS staff relayed several calls had been received from people who were concerned about Dr. Sobus leaving the state and the subsequent access problems this created.
- Lisa Beckman, Lori Hanson, Donene Feist, and Cheryl Klee all agreed to serve for another two-year membership term. Tammy will update the Family Advisory Council membership list and distribute it at the next meeting.
- Bylaws were reviewed without any changes. Tammy will change revision dates from May 2005 to May 2006.

Updates:

National Update

- AMCHP now has two director at-large seats reserved for family liaisons to state Title V programs. A coalition has been re-established to obtain broad-based support called *Friends of Title V*.
- Public health training is available through the Rocky Mountain Public Health Education Consortium, which offers a MCH Certificate Program and a MCH Public Health Summer Institute. CSHS staff are interested in participating but the time commitment required to attend has been an issue.
- MCHB invited Title V staff to attend a technical assistance workshop titled *From Needs Assessment to Strategic Action: The Important Journey*. No one from ND was able to attend because of other work demands.
- New MCH Block Grant guidance was finally received for the grant due July 15, 2006. The same guidance will be used through May 2009.

Department of Human Services Update

- Tammy shared the *Executive Summary of 2006 DHS Public Stakeholder Meetings*. Themes that emerged will be reviewed as the department develops the budget for the next biennium. Donene relayed that children with special health care needs were not specifically included, although concerns about the ability to meet the needs of individuals with physical disabilities was mentioned along with the need for more home and community-based services.
- Tammy provided an update on the Budget Committee on Human Services. At the March 9, 2006 meeting, Maggie Anderson testified on the status of the Medicaid waiver to provide in-home services to children with extraordinary medical needs. This waiver will be submitted in 2006 with an effective date after the beginning of the next biennium. The Katie Becket Eligibility Option and Medicaid Buy-In Program were also briefly mentioned. Another committee meeting is scheduled for May 31, 2006. Legislative Council staff have asked for information about CSHS in order to complete a comparison report of surrounding states CSHCN programs.
- The Medical Needs Task Force met on March 22, 2006. Tammy and Deb Balsdon keep the group updated on the status of the waiver and new developments related to the child health study. The group provides stakeholder input to the department. Major focus has been on completion of a prevalence and cost study. Future focus will be on prioritizing service needs. The waiver will likely be written this summer using a team approach. The task force will meet again in May 2006.

- Tammy relayed that the Deficit Reduction Act provides states with an opportunity to implement a Medicaid Buy-In Program for children birth through age 18 meeting SSI disability criteria up to 300% of the federal poverty level. The department is preparing a fiscal analysis for this option. Donene relayed that the ND Disability Advocacy Consortium has chosen the Medicaid Buy-In Program as a legislative priority.
- Tammy relayed DHS has established waiver teams to coordinate waiver-related activities within the department.
- Tammy relayed that the biennial budget process is underway within DHS.

Review of CSHS Medical Advisory Council Meeting:

Sue reviewed highlights of the Medical Advisory Council meeting. Members will receive minutes of this meeting when they are distributed by CSHS. Twyla attended the meeting and provided an update on behalf of the Family Advisory Council. Agenda topics included provider qualifications, medical eligibility, covered services/reimbursement issues, programmatic updates, and discussion about the system of care for children with special health care needs and their families. Donene relayed concerns about the availability of home and community-based services for individuals on ventilators.

CSHS Systems Report:

Kora provided a brief update on medical home. A team has been involved in collaborative training in Minnesota. Members of the team gave a presentation at the May 2006 ND Chapter of American Academy of Pediatrics meeting. Over the next year, a steering council will be formed and practice implementation pursued. Due to lack of time, this topic will be revisited at a future meeting.

IDEA Slide Show:

A slide show on IDEA was presented to council members. Donene requested that a copy of the PowerPoint be sent to her in follow-up to the meeting.

CSHS Annual Plan for the MCH Block Grant:

Family Advisory Council members reviewed the FFY 2007 Annual Plan for the MCH Block Grant and gave the following suggestions:

- FPM #1 Newborn screening – 1) Include metabolic information in the Family Voices newsletter, and 2) Include outreach presentations to Infant Development, Right Track, and DD Case Management staff in next year's public information plan.
- FPM #2 Families partnering in decision-making and are satisfied with services – 1) Consider the help of family organizations in conducting the CSHS telephone survey.
- FPM #3 Medical home – 1) Consider use of a more research-based approach with the medical home pilot (e.g.) do more than one pilot, develop a protocol, define challenges and opportunities, etc.
- FPM #4 Insurance – 1) Work with partners in supporting outreach about health coverage options and health benefits counseling/training (e.g.) family organizations, Insurance Commissioners Office, etc.
- FPM #5 Community-based system – 1) Include the following activity "CSHS will partner with and promote the use of family organizations toll-free numbers to assist families in locating services".

- SPM #8 Assessment and planning for children with extraordinary medical needs – 1) Partner with others to monitor the status for this measure; include viewpoint outside of CSHS staff.
- SPM #9 Families who had no problem getting care from a specialist doctor – 1) partner with others to monitor the status for this measure; include viewpoint outside of CSHS staff.
- SPM #10 Activities completed in CSHS Public Information Services plan – 1) Conduct outreach to Developmental Disabilities staff and Regional Interagency Coordinating Council's.

Family Participation Ranking:

Family members were asked to rate six characteristics measuring the degree of family participation in the CSHS program. After CSHS staff members also independently rank the characteristics, the two will be combined. The average overall ranking will then be submitted on form 13 in the MHC Block Grant application titled *Characteristics Documenting Family Participation in CSHCN Programs*.

Open Discussion:

Family Advisory Council members gave the following recommendations for county and public health care coordination training topics:

- Medical home
- Transition at age 18
- Health benefits counseling support

Reimbursement forms/Adjourn:

Reimbursement forms were completed and the meeting adjourned.

Next Meeting: Saturday, August 19, 2006 from 9:00 – 12:00 noon